

COUPLES' EXPERIENCES FACING PROSTATE CANCER: RELATIONAL
DISTRESS, COMMUNICATION, AND SEXUAL DYSFUNCTION

A THESIS

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BY

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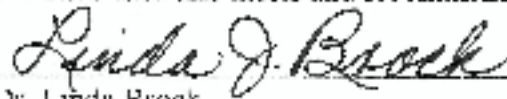
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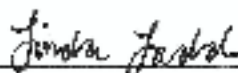
To the Dean of the Graduate School;

I am submitting herewith a thesis written by Kristin Ashley McDaniel entitled "Couple's Experiences Facing Prostate Cancer: Relational Distress, Communication, and Sexual Dysfunction." I have examined this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Masters of Science with a major in Family Therapy.


Dr. Sarah Woods, Major Professor

We have read this thesis and recommend its acceptance:


Dr. Linda Brock


Dr. Linda Ladd


Department Chair

Accepted:


Dean of the Graduate School

DEDICATION

For my Mom and Dad, Taylor, Nanee, and Grammy. Thank you for all of the sacrifices made and love given to get me here. To Oma, Opa, Grandpa Floyd and Grandpa. While you may be gone, I know you are all watching and protecting me. Thank you for being my guardian angels and making sure I could be here to make you proud.

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ABSTRACT

KRISTIN ASHLEY MCDANIEL

COUPLES' EXPERIENCES FACING PROSTATE CANCER: RELATIONAL DISTRESS, COMMUNICATION, AND SEXUAL DYSFUNCTION

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The purpose of this qualitative study was to evaluate the relationship between prostate cancer and relationship distress in couples. The study produced several themes that answered the three research questions. Six couples participated in a face to face interview. Themes identifying communication were as follows, (1) positive healthy communication and (2) communication issues. Themes identifying gender differences were, (1) gender differences in distress. Several themes were identified for how couples experience distress some of them include, (1) distressing emotions, (2) medical and treatment side effects, (3) maintaining normalcy, (4) lack of support from medical providers and several others. Findings were similar to those found in other studies; however, it was found that couples find it important to advocate to others. It was also found that couples experience gender differences when looking at distress.

TABLE OF CONTENTS

	Page
DEDICATION	iii
ACKNOWLEDGMENTS	iv
ABSTRACT.....	vii
LIST OF TABLES	x
 Chapter	
I. INTRODUCTION	1
Prostate Cancer	1
Sexual Dysfunction, the Couple, and Communication	2
Statement of the Problem.....	3
Purpose of the Study	5
Summary	5
II. LITERATURE REVIEW	6
Prostate Cancer and Couples Relational Distress	6
Sexual Dysfunction	7
Communication.....	11
Communication about Prostate Cancer.....	12
Communication about Distress	13
Communication about Sexual Dysfunction	14
Summary	14
III. METHODOLOGY	16
Sample	16
Recruitment.....	17
Procedure	17
Measures	18
Demographic and Medical History Questionnaire	18

Interview Questions	19
Data Analysis	19
Self of the Researcher	20
IV. RESULTS	22
Couples' Experience of Distress	22
Distressing Emotions	23
Medication and Treatment Side Effects.....	24
Lack of Support or Information from Medical Professionals	25
Approaches to Coping.....	29
Healthy Lifestyle Changes	31
Changes in Intimacy	32
Advocacy	33
Gender Differences in the Experience of Distress	34
Communication About Distress.....	36
Communication Issues	37
Positive, Healthy Communication	38
Summary	40
V. DISCUSSION	41
Similarities to Previous Research	41
Dissimilarities with Previous Research	43
Gender Differences & Advocacy.....	45
Clinical Implications	46
Limitations and Future Research	47
Conclusion	49
REFERENCES	70
APPENDICES	74
A. Demographic and Medical History Questionnaire	74
B. Recruitment Material	80
C. Consent	83
D. IRB Approval.....	88

LIST OF TABLES

Table	Page
1. Research and Interview Questions.....	51
2. Themes and Sub-themes	54

CHAPTER I

INTRODUCTION

Chronic illness, including cancer, is on the rise (Kowal, Johnson & Lee, 2003); the overall cancer rate is expected to increase by 45% in the next 15 years (U.S. Senate Special Aging Committee, 2014). According to the Centers for Disease Control and Prevention (2013), as of 2010, the leading causes of death were heart disease and cancer. Recent research lead by the U.S. Senate Special Aging Committee (2014) suggests that cancer could possibly become the number one cause of death in America in the next 16 years. Specific to prostate cancer, it is estimated that there are 3 million survivors; this number is expected to grow to 4.2 million in the next 10 years (Cowens-Alvarado, 2014). Prostate cancer is the most common male cancer and usually effects males over the age of 55 (Bohmer & Clark, 2001; Chambers et al., 2013; Harden et al., 2002; McCaghan et al., 2013).

Prostate Cancer

Prostate cancer that is detected early has a high survival rate. However, surviving cancer does not free the patients of possible side effects, ranging from physical to relational (Cowens-Alvarado, 2014). Many men face urinary inconsistency, erectile dysfunction, and fatigue (Bohmer & Clark 2001; Harden et al. 2002; Walker & Robinson, 2010). Men are also often affected sexually and emotionally by these physical symptoms, leading to loss of libido and lowered self-esteem (Harden et al., 2002; Navon

& Morag, 2003; Walker & Robinson, 2010). Tan, Waldman, and Bostick (2002) found that most sexual functioning issues affecting prostate cancer patients stemmed from the treatment and not the diagnosis of cancer. There are many different types of treatment for cancer and each treatment affects sexual functioning differently. Radiation greatly affects sexuality, while chemotherapy is more associated with physical fatigue. In addition, treatment side effects, including fatigue, hair loss, weight gain, and scarring additionally affect sexual functioning (Flynn et al., 2011).

Sexual Dysfunction, the Couple, and Communication

Additionally, Harden et al. (2002) found that spouses are affected by the cancer's symptoms, such as sexual dysfunction, hormonal changes, and urinary dysfunction. McCaughan et al. (2013) found that partners of patients with prostate cancer can be more affected by the side effects of prostate cancer than the patient. It is speculated that while the patient has distress about the diagnosis and post-treatment, female partners have a higher level of overall distress (Chambers et al., 2013; Gray et al., 2000; Gray et al., 1999). Gray et al. (1999) speculate that the amount of medical information a spouse receives affects her level of distress. In other words, little or no medical information given to the spouse is related to higher distress. This pattern of distress may be an overarching pattern seen in many couples facing chronic illness, as seen in a study of couples facing chronic illness. Kowal et al. (2003) describe a reoccurring cycle between chronic illness and couple relationships. In this cycle the illness impacts the couple which in turn impacts illness. This cycle may play a significant role in how couples interact

during and after cancer, this may also explain the higher levels of distress female partners face (Kowal et al., 2003).

Couples find it important to discuss their fears and concerns with their partners; when not discussed, partners create emotional distance between one another to avoid feeling inadequate (Flynn et al., 2011). However, couples with prostate cancer, who experience sexual dysfunction do not typically discuss these problems as a couple, nor with family or friends (Boehmer & Clark, 2001; McCaughan et al., 2013). Despite the fact that, couples facing prostate cancer were able to dissipate their anxieties throughout the diagnosis and treatment phases by communicating with one another (Gray et al., 1999).

Statement of the Problem

While some research has found that chronic illness can affect romantic relationships, other research has found that it does not have an effect or that it is unrelated. In some couples, for instance, their relationship can help increase chances of successfully fighting an illness (Kowal et al., 2003). In some cases, spouses describe feeling closer to one another, due to their ability to be more intentional when spending time together (Harden et al., 2002; Lavery & Clarke, 1999). In contrast, couples in more distressed relationships tend to experience a decrease in health when facing an illness that is temporary or chronic (Kowal et al., 2003). In addition, relationships often increase in distress with the diagnosis and treatment of chronic illness, such as, cancer, heart disease, and diabetes (Kowal et al., 2003). Despite these findings, a small majority felt that the

changes they experienced did not impact their romantic relationship (Lavery & Clarke, 1999). The differences between these findings may be due to differences in illnesses. While some chronic illnesses may be constant and severe others may be less constant and mild (Kowal et al., 2003).

Specific to prostate cancer, there is little research investigating the effects of prostate cancer on marriage (Bohmer & Clark, 2001; Gray et al., 1999; Harden et al., 2002). In addition, Gray et al., (2000) found that, while it is known that women face higher distress than their male partners with prostate cancer, there are inconsistent reasons as to why. These authors postulated that this distress difference may be due to gender roles, although they explain that no research currently exists to support this speculation. There may also be a difference in partner reactions to prostate cancer due to timing of the illness; distress may occur for each spouse at different parts of the diagnosis and treatment process (Kornblith, Herr, Ofman, Scher, & Holland, 1994). Another possibility is that women and men cope differently with a prostate cancer diagnosis; women may need more emotional support than men, who may benefit more from informational support (Gray, Fitch, Davis, & Phillips, 1996). Nonetheless, Manne et al. (2010) suggest that researchers examine the association between treatment symptoms and couples communication about sexuality, as well as couples sexual functioning before prostate cancer diagnosis.

The dearth of relational research pertaining to prostate cancer and couples, as well as the disparate foci and results, affects our ability to understand couples' reactions to the

diagnosis, treatment, and one another. More research is needed to determine the relationship between prostate cancer and female partner distress.

Purpose of the Study

The purpose of this qualitative study is to evaluate the relationship between prostate cancer and relationship distress in couples. The following research questions will guide the research:

- 1) How do couples facing prostate cancer experience distress, and why? How is the distress connected to sexual dysfunction related to prostate cancer and its treatment process?
- 2) Do female partners experience distress differently than the male patient? If so, why? And, is distress for the female partner connected to experience of sexual dysfunction?
- 3) How do couples communicate about stressors? Do individuals think their partner knows they are distressed? Does the partner *actually* know?

Summary

In summary, the purpose of this study is to look at the distress experienced by couples facing prostate cancer. How men and women partners experience this distress differently. As well as, how partners communicate about distress with one another. Additionally this study will look for any relationship between distress and sexual dysfunction.

CHAPTER II

LITERATURE REVIEW

When facing cancer or chronic illness, some patients may experience physical symptoms. Those with severe or multiple symptoms may have partners that are not as supportive as those with limited or no symptoms (Manne et al., 2010).

Prostate Cancer and Couples Relational Distress

Different types of cancer affect males and females, as well as sexual functioning and intimacy, differently (Tan et al., 2011). Prostate cancer has high rates of erectile and urinary dysfunction. These dysfunctions impact the patient's psychological and social well-being, and these men often have high levels of distress (Manne et al., 2010). This in turn impacts males' female partners, and often leads to women (i.e., wives) having higher distress than the male patients. The reasons for this higher level of distress is unclear. The side effects of prostate cancer treatment is unique to this type of cancer. Therefore, couples facing prostate cancer have a different set of concerns and obstacles to face as compared to other couples facing cancer. This different experience can lead to sexual and emotional deficits in the couple (Manne et al., 2010).

Couples facing prostate cancer experienced unique symptoms of treatment, as well as significant impacts on the relationship. The effect that prostate cancer has on relational distress and satisfaction has not been effectively researched (Boehmer & Clark, 2001; Harden et al., 2002; Lavery & Clark, 1999). Men tend to face higher levels of

distress when facing prostate cancer if they are in an already less satisfactory relationship. This relational satisfaction plays a more important role in the patients' experience than the partners' (Manne et al., 2010).

Harden et al. (2006) found that wives who continued to work while their partner was treated for prostate cancer had higher levels of distress than those who did not work. It was also found that women had a higher tendency to monitor changes, physically and emotionally (Harden et al., 2006). Women who had these higher monitoring levels had difficult moving past the cancer (Harden et al., 2006). These findings may explain the higher levels of distress that women face. However some women found themselves worrying often about the possible outcomes of the prostate cancer and how these would affect their lives (Harden et al., 2002; Harden et al., 2006).

Sexual Dysfunction

It is speculated that partners may face higher relational distress due to caregiving for the patient (Boehmer & Clark, 2001). Cancer causes fatigue and physical weakness, which requires the well partner to care for the partner with cancer. This caregiving shift can cause role changes that affect sexual functioning (Lindau et al., 2011; Tan et al., 2011). Tan et al. (2011) found that while both partners were affected by sexual dysfunction, the partner with cancer reported higher levels of sexual dysfunction. Specific to couples experiencing breast cancer, some women undergoing treatment were able to overcome sexual dysfunction by redefining their sexuality, which helped the couple regain sexuality and intimacy (Tan et al., 2011). In addition, some couples

experiencing breast cancer were able to redefine sexuality, changing it from sex to intimacy (Flynn et al., 2011). Lastly, some couples experiencing cancer are able to use the effects of cancer to better their relationship. Couples who once saw intimacy as sex only were able to broaden their sense of intimacy. These couples were able to find new ways to be close to one another (Flynn et al., 2011; Lindau et al., 2011). Intimacy can help couples deal with the stress of cancer, in part because it contributes to increased sexual functioning. Many couples found that being forced to create other forms of intimacy outside of sexual intercourse, such as hugging and hand holding, gave them more patience than they had before cancer, which in turn allowed them to eventually return to having sex. It is apparent that intimacy is important during cancer and can help elevate fears and restore sexual functioning (Flynn et al., 2011; Lindau et al., 2011).

Cancer brings on fears and feelings of loss, which affect sexual functioning (Lindau et al., 2011). In addition, the level of sexual functioning before a cancer diagnosis predicts possible sexual dysfunctions during and after treatment (Tan et al., 2011). Nonetheless, sexual and physical side effects, of all cancers, can last years after the successful treatment of cancer (Flynn et al., 2011). While surviving cancer is priority number one for patients and their families, maintaining intimacy and sexual functioning allows for a sense of normality through treatment, and for both patients and partners (Flynn et al., 2011; Lindau et al., 2011).

There are many different types of treatment for cancer, each treatment affects sexual functioning differently (Flynn et al., 2011). Radiation greatly affects sexuality,

while chemo was more associated with physical fatigue (Flynn et al., 2011). Tan et al. (2002) found that both men and women had low sexual functioning during cancer treatment. Certain treatment side effects tend to effect sexual functioning more than others. Fatigue, hair loss, weight gain, and scarring are among those that affect sexual functioning (Flynn et al., 2011). Of all cancer patients who receive treatment for cancer, those receiving treatment for a cancer affecting a sexual organ report the most diminished sexual functioning (Flynn et al., 2011).

Often sexual dysfunction accompanies prostate cancer, at times impacting the couple's relational quality (Lavery & Clarke, 1999). In an interview of couples facing prostate cancer, it was found that a majority of patients suffered from some level of sexual dysfunction. (Lavery & Clarke, 1999). Of men diagnosed with prostate cancer, suffer from sexual dysfunction (Badr & Charmack-Taylor, 2009). Often the importance of sexual dysfunction as a symptom of prostate cancer is not discussed between partners. In one study, it was found that both the partner and patient had concerns and fears around effects, such as, sexual loss, death and dependency, associated with prostate cancer, but did not discuss it with one another (Boehmer & Clark, 2001). Some patients had concerns that sexual dysfunction would impact their partners more than them, while others felt more impacted by fears of rejection and inadequacy (Lavery & Clarke, 1999).

Due to the age that most prostate patients are diagnosed, some may have struggled with sexual dysfunction before prostate cancer (Boehmer & Clark, 2001). This may be part of the reason why some couples feel that sex is only a part of their relationship and

did not impact their overall satisfaction with their relationship (Lavery & Clarke, 1999). Some of a couple's sexual functioning, however, is determined by how a couple's sexual functioning was, before the cancer diagnosis and treatment (Tan et al., 2011).

Prostate cancer negatively affects sexuality more than other types of cancer, with effects, such as, erectile dysfunction and loss of libido (Tan et al., 2002; Walker & Robinson, 2010). The effects of prostate cancer on sexuality may be, in part, because of androgen deprivation therapy (ADT), a type of treatment used specifically for prostate cancer. Walker and Robinson (2010) found that, similar to other types of cancer, prostate cancer patients suffer from tiredness, loss of sexual desire, and lack of self-esteem.

Although, universally, there are cancer treatment side effects that may affect sexual functioning, there are also gender differences in how men and women perceive the importance of multiple aspects of their sexual functioning. While both genders find sexual difficulty frustrating, men report dissatisfaction with sexual dysfunction more frequently than women. When comparing the patient and partners in couples, it was found that the male patient of prostate cancer were concerned with sexual functioning and the treatment of their cancer (Manne et al., 2010) This difference is lessened, however, if both partners in the relationship have medical issues; in this case, the frustration of the male partner is lessened (Flynn et al., 2011). Erectile dysfunction has been identified as the main concern for men with prostate cancer (Gray et al., 1999; Flynn et al., 2011; Tan et al., 2002). The sexual side effects of prostate cancer, such as,

erectile dysfunction can often be contributed to self-esteem issues for male patients (Flynn et al., 2011).

Due to all of the effects that prostate cancer has on sexuality and thus relational distress it is important to look at the relationship between prostate cancer, communication and distress (Walker & Robinson, 2011). It was found in one study, that only 20% of those who undergo ADT will be able to regain sexual functioning (Walker & Robinson, 2011). With percentages so low it is important for research to expand in this field to better help couples adjust to life after prostate cancer (Walker & Robinson, 2011). Just as important are the findings of one study, which found sexual dysfunction to be negatively associated with distress and marital satisfaction (Badr & Charmack-Taylor, 2009). With such impact on distress and marital adjustment and little research done in this area it is important that researchers look closer at their association (Badr & Charmack-Taylor, 2009).

Communication

There is little research on couples facing prostate cancer and their communication. However the research that has been done shows that couples have difficulty communicating. In general couples communicate little about the diagnosis, their concerns and worries, or the sexual dysfunctions that accompany prostate cancer. Women tend to want to share their feelings and worries about the prostate cancer experience, however, they hesitate when it comes to actually sharing (Manne et al., 2010). This hesitation may be due to fear of causing concern in their partner that was not there before (Boehmer &

Clark, 2001; Decker, Pais, Miller, Goulet, Fifea, 2012; Lavery & Clarke, 1999; Lindau et al., 2011). Some partners may feel that by avoiding the topic they can prevent the patient from having these concerns. Similar to their partners, patients also avoid expressing their feelings and worries with their partner, in hopes that their partner would not share their concerns (Boehmer & Clark, 2001; Decker, Pais, Miller, Goulet, Fifea, 2012; Lavery & Clarke, 1999; Lindau et al., 2011).

Communication about Prostate Cancer

Partners with any chronic illness or disease, and their partners, benefit from open communication (Boehmer & Clark, 2001; Lavery & Clarke, 1999). Partners of couples facing prostate cancer found that they were more hopeful when they were able to discuss the disease with the patient (Manne et al., 2010). While research indicates that communication helps partners decrease distress and increase relational satisfaction, it is yet unclear how communication impacts patients. It is also unclear how the type of communication such as mutual avoidance, where both partners avoid communication; patient demand- partner withdrawal, where the patient seeks communication and the partner avoids; and mutual constructive communication, where both patient and partner communicate, impacts these feelings of hopefulness (Manne et al., 2010). Boehmer and Clark (2001) speculated that, during the diagnosis and treatment process, patients may believe they are sharing their feelings when in fact they are not.

Communication about Distress

Little research has been done on couples facing prostate cancer. Far less research has examined the impact of communication on distress and relational satisfaction for couples experiencing prostate cancer (Gray et al., 1999; Manne et al., 2010). It is speculated that communication may have an impact on distress and relationship satisfaction. It has been found that when both partner and patient discuss their feelings and concerns both have lower distress levels. One research study found that partners that held back concerns had higher distress levels compared to the cancer patient holding back concerns (Manne et al., 2010). Communicating, both during and after prostate cancer treatment, can help alleviate some distress for partners (Decker et al., 2012; Lindau et al., 2011; Manne et al., 2010). Despite this, previous research has found that there is low communication around prostate cancer; however, it was found, that prostate cancer couples do communicate openly (Manne et al., 2010). Given the few, and conflicting, findings, it is critical that researchers look at why some couples have more open communication while others have less open communication (Manne et al., 2010).

When looking at communication, one study found that partners saw talking to one another about their fears as an important role for reassurance (Gray et al., 1999). Those that avoid sharing these feelings may have higher distress and lower relationship satisfaction. It was found in a study, specific to prostate cancer, done by Manne et al. (2010) that both partners avoid communication and couples in which the patient wants to share and the partner does not, had lower relationship satisfaction and higher distress. It is

speculated that patients may not want to share due to wanting to quickly move beyond prostate cancer. Despite these good intentions, this behavior has a negative relationship with marital satisfaction and a positive relationship with distress for both partner and patient (Boehmer & Clark, 2001; Lavery & Clarke, 1999).

Communication about Sexual Dysfunction

Often couples do not discuss the impact of sexual dysfunction on their sexual relationship. Men describe discomfort around having to share feelings about sexual dysfunction due to prostate cancer (Manne et al., 2010). Couples, however, do discuss sexual dysfunction when weighing treatment options. During this time, couples discuss the downsides of sexual dysfunction, but many feel that sexual dysfunction is much preferable to losing the fight against prostate cancer (Boehmer & Clark, 2001; Gray et al., 1999). Despite this open discussion at the beginning of treatment, many couples stop discussing sexual dysfunction after proceeding with treatment (Boehmer & Clark, 2001). When compared, this population discusses sexual dysfunction less than those not facing illness (Manne et al., 2010).

Summary

Research in the area of prostate cancer, communication, sexual dysfunction and distress is severely limited (Badr & Carmack-Taylor, 2009). The findings of studies done in this area have found that women partners experience higher distress for uncertain reason (Gray et al., 2000). Others have found that lesser communication leads to higher distress (Manne et al., 2010). Perhaps, indicating that more, open communication leads to

lower distress and higher marital satisfaction. However these findings are conflicted with others that indicate that communication is not linked with distress, as couples facing prostate cancer do communicate openly (Manne et al., 2010). When looking at sexual dysfunction there are disparities as to whether or not couples communicate about their concerns (Boehmer & Clark, 2001). With all of these opposing findings this study hopes to add to the field and also help clarify these findings.

CHAPTER III

METHODOLOGY

The purpose of this qualitative study was to evaluate the relationship between prostate cancer and relationship distress in couples. The following research questions guided the research:

- 1) How do couples facing prostate cancer experience distress, and why? How is the distress connected to sexual dysfunction, related to prostate cancer, and related to the treatment process?
- 2) Do female partners experience distress differently than the male patient? If so, why? And, is distress for the female partner connected to experience of sexual dysfunction?
- 3) How do couples communicate about stressors? Do individuals think their partner knows they are distressed? Does the partner *actually* know?

Sample

Participants were males who have been diagnosed and treated for prostate cancer and their female partners. Inclusion criteria include that both male and female partners must be at least 18 years of age, and able to read, speak and comprehend English, similar to previous research in this area (Harden et al., 2006). Couples needed to be in a committed relationship, defined as either married or cohabiting but unmarried. This study included six couples. Male patients were a mean age of 74 (range of 54 to 93) and their

female spouses had a mean age of 70 (range of 51 to 89 years). All participants were married with the majority being married for over 40 years. Two couples had been married for 20-24 years. These two couples were also 51-60 years old at the age of onset of prostate cancer. All other participants were 61-70 at the age of onset. Three participants were diagnosed with stage 1 prostate cancer. One couple was diagnosed with stage 4; the remaining two were diagnosed with stage 2 prostate cancer. One female spouse also had a previous history of thyroid cancer. In addition to prostate cancer, one male participant suffered from heart disease, while another male patient had stage 4 neck cancer previous to prostate cancer as well as hyper/hypothyroidism. Two female spouses had heart disease. All but one participant was Caucasian, while one male participant identified as Hispanic. Education levels ranged from high school/GED to master's degree, with a majority of women having some college.

Recruitment

Participants were recruited through prostate cancer support groups in the Dallas/Fort Worth area. Individuals who manage the prostate cancer support groups distributed IRB-approved flyers and emails to their support group participants. Those who were willing to participate contacted the researcher by phone or email.

Procedure

After Internal Review Board (IRB) approval was received the researcher contacted the support group leaders. Once participants scheduled an interview they were asked to fill out a consent form before the interview began. After the consent form was

filled out participants filled out a demographic and medical history questionnaire prior to the interview starting (Appendix A).

In a study done by Gray et al. (1999), interviews were conducted with couples and individual partners to allow the couple to separately disclose their own individual experiences. Therefore, the researcher conducted interviews with both the couple and partners separately. Participants were allowed to choose where interviews were conducted. Examples include the couple's own home and local libraries. Interviews were semi-structured to allow for the couples to discuss what they felt was important, similar to previous research (Harden et al., 2006). Interviews lasted 30 minutes to an hour and a half, and were recorded with a voice recorder. The use of a recorder was described in the approved consent form.

Measures

Participants filled out a demographic and medical history questionnaire, similar to previous research (Harden et al., 2006). Table 1 contains the interview questions that the researcher asked the couple and partners. The interview consisted of 18 open ended questions.

Demographic and Medical History Questionnaire

The demographic and medical history questionnaire asked questions about the couple's age, age of diagnosis, sex, ethnicity, race, education level, length of relationship, marital status, and prostate cancer treatment type, as well as questions pertaining to past medical conditions for both partners.

Interview Questions

It is evident that the literature has limited research on couples facing prostate cancer, their distress, communication and sexual dysfunction (Badr & Carmack-Taylor, 2009). Therefore, the interview questions used in this qualitative study are reflective of both previous research (Gray et al., 1999; Harden et al., 2002; Harden et al., 2006) and the present research questions, in order to best expand the research on prostate cancer and couples. A majority of these questions were asked to both partners, while some were asked to only the prostate cancer patient. This is due to the fact that certain aspects of the illness can only be experienced by the patient. Interview questions in Table 1 are grouped by their association with the research questions to ensure that the questions are thoroughly addressed.

Data Analysis

The researcher transcribed all interviews and identify themes using grounded theory methods for qualitative analysis (Strauss & Corbin, 1990), similar to previous qualitative research with couples experiencing prostate cancer (Boehmer & Clark, 2001). Grounded theory was chosen because the process helps establish themes based on the identified situation, how individual participants react uniquely to situations, and the effects their reactions have (Strauss & Corbin, 1990). Therefore, a grounded theory approach takes seemingly different reactions and situations and establishes a common ground (Strauss & Corbin, 1990).

Open and axial coding was used to identify themes found throughout the interviews. Open coding is a method where data is blocked into groups of raw data and evaluated for concepts based on properties and dimensions. Axial coding is a method of relating concepts identified in open coding (Corbin & Strauss, 2008). The researcher included a doctoral Family Therapy student in the research team in order to help create codes and identify themes. The research team included three coders in total (the author, the author's advisor, and the doctoral Family Therapy student volunteer); three coders were used in a method called triangulation. This method is used to have different viewpoints when coding, in order to increase the validity of the study (Harris-McKoy, Woods, Brantley, & Farineau, 2014; Saldaña, 2011).

A method known as constant comparison, a type of comparison where the researchers compare different pieces of data to one another to find differences and similarities, was used in this study (Corbin & Strauss, 2008). The research team discussed any disputes on themes to establish consistent themes. The data analysis methods of this study are reflective of those commonly used in the field of qualitative research, and prostate cancer and couples (Boehmer & Clarke, 2001; Gray et al., 1999; Harden et al., 2006; Lavery & Clarke, 1999; Navon & Morag, 2003; Walker & Robinson, 2011).

Self of the Researcher

I am a bi-racial, bi-national woman, who identifies as both black and white, American and Dutch. I grew up in a middle class military home. During my childhood I experienced Acute Lymphoblastic Leukemia, during a time where survival of childhood

cancer was only at 75%. Due to my father's employment with the United States Army, my treatment was covered free of charge outside of travel expenses. As a teenager I was diagnosed with hyperthyroidism due to an enlarged thyroid which was subsequently removed. I have since experienced hypothyroidism along with other chronic health issues that have impacted my family and my partner's lives. I have spent the last few years in graduate school working towards becoming a marriage and family therapist. As a researcher I acknowledge that all of these experiences in my life have the potential for impacting research. Due to the qualitative approach in this study I have use a tridatic coding team as a way to check for researcher bias. I have also remained aware of my biases through reflective thinking. As well as meeting with my thesis advisor and discussing any potential biases.

CHAPTER IV

RESULTS

This results section presents the findings of the qualitative analysis of the data collected from 6 couples experiencing prostate cancer diagnosis and treatment. Participants' answers are reflective of the interview questions (Table 1) and are tied back to the project's original research questions. Each qualitative theme will be defined and described, and example participant quotations elucidating the theme will be presented. Further information on each theme, subtheme, and the number of participants who provided data connected to each theme, along with example quotations, is provided in Table 2. All themes discovered are provided in Table 2; no subthemes for which a sole participant provided data ($n = 1$) are discussed in this Chapter, however. In other words, the research team discussed all themes that emerged from the qualitative analysis, but declined to include subthemes as part of the second-level axial coding if data for that subtheme was representative of only one participant.

Couples' Experience of Distress

The first themes discussed addressed the following research question: *How do couples facing prostate cancer experience distress, and why? How is the distress connected to sexual dysfunction, related to prostate cancer and its treatment process?*

The research team found the following themes (axial codes) in the data connected to this initial research question: distressing emotions, medication and treatment side effects, lack

of support or information from medical professionals, approaches to coping, healthy lifestyle changes, changes in intimacy, and advocacy.

Distressing Emotions

This theme (axial code) had eight subthemes including: feelings of anger, fatigue, depression, anxiety, feelings of regret surrounding the loss of sexual functioning, fear of loss and death, and feeling emasculated and/ or demeaned. All couples experienced distress through these emotional experiences. Some of these emotions, such as fatigue and anger, were on occasion linked to side effects of medication. An example includes the male partner from interview four, who explained his experience in the following way: “unless I’m on hormone therapies, uh, at which time you are limited, uh, because of fatigue....” An additional example includes one couple who described feelings of regret surrounding the loss of sexual functioning: “If we had known that...that regret I have is that we didn't really have one really good night of just intimacy before he started that prep, or even earlier,” referring to her husband’s evening of preparatory steps prior to surgery for his prostate cancer. While only two couples experienced a fear of loss and death, these couples also expressed fear around losing normal functioning. In addition, two male patients described feeling emasculated and demeaned. For example the couple from interview six described certain side effects as demeaning:

Female: Pads, we used pads.

Male: We had to, at the very beginning I had pads.

Female: You used my pads. (laughs)

Male: Yeah...it uh...

Female: But we worked it out.

Male: Yeah, the man me, had to uh...

Female: It's demeaning.

Male: Uh, well...

Female: It's demeaning.

Male: It takes away the macho part of me in this.

There was a distinctive difference between feeling emasculated (and feeling less like a man) and feeling demeaned, the latter of which included feeling embarrassed, awkward, and lowered in dignity.

Medication and Treatment Side Effects

This theme had two subthemes which included: medication/treatment side effects and sexual dysfunction. All couples reported some form of medication or treatment side effect. One major side effect of treatment, that most couples discussed, was urinary incontinence. Many couples who experienced this symptom reported continuing to have difficulties, whether minor (e.g., leakage due to urinary incontinence) or major (e.g., requiring the frequent use of pads due to urinary incontinence). Sexual dysfunction was present among all participants. All couples reported having sexual functioning (i.e., all couples denied having concerns about their sexual functioning or sexual relationship) before experiencing prostate cancer treatment, followed by a lack of functioning after

treatment. One male partner from interview four explains his experience with both urinary incontinence and sexual dysfunction:

Well, I, uh she has been very understanding, uh, um... Although, I had was, far as, I had two issues, incontinence and um, erectile dysfunction as a result of the surgery. As far as the, uh, the incontinence, she's been very supportive. And, um, and since she's a nurse she, she helped out and gave me the proper, the pads that um, that uh, pads that I can use. So, she's been really good at that. Um, as far as um, the sexual situations, she has been very understanding.

All participants described the sexual dysfunction following treatment as the inability to maintain or achieve an erection, also known as erectile dysfunction. However, the erectile dysfunction did not mean that couples were unable to achieve orgasms. Many couples reported that they were unable to have intercourse, but reported that they are able to have an orgasm, although several participants reported their experience of orgasm was different than before treatment.

Lack of Support or Information from Medical Professionals

Related to the couples' experiences of distress were their reports of a lack of support or relevant, necessary information from medical professionals encountered. Within this domain, the research team identified four subthemes: physician insensitivity to psychosocial issues and patient differences, ambiguity in treatment options/outcome, ambiguity in future sexual functioning, and dissatisfaction with medical provider.

Two couples described receiving medical care that was not patient-centered, meaning neither their unique reactions to treatment nor their psychosocial concerns were validated.

One wife described the couple's experience:

We were kind of disappointed um, he was disappointed in his doctor. He, he, was not crazy about how his doctor related to him. We, we, did find another doctor that was in his same group, but much more receptive to him and much more a better bedside manner. So I think from that standpoint he's, she's done better, he has more confidence in the second doctor. The first doctor would say these things and it kind of sounded like a little bit offhand to him. Like. You know, like its okay, you know, like that kind of thing. And I don't think he [husband] was prepared to hear what he did hear the first time we were seen by the doctor. I think probably if I were to recommend anything I would think, people that get the diagnosis, unless they say it's at Stage IV, that you should go at least for second opinion, to another surgeon, and then, or go back to the same doctor and review everything.

These experiences of insensitive care from medical providers often led to overall disappointment with medical providers, as well as couples' choices of cancer treatment.

The above couple also explained:

Then, with the fact that he, that should have been a red flag whenever he called a couple times. Like you're pushing the issue okay, you got to do something that, that... That time I should've just, should've been red flag and I need to get a

second opinion and, um, but I didn't, I didn't. And after the surgery, uh, that the doctor would not respond to my phone calls. I have my catheter seemed like urine was coming outside of the catheter. And um ,had to use a catheter for two weeks and then I'll, I won't get a call back from the doctor or the nurse so, and I cannot blame that lack of, that lack of, lack of, not interest but lack of action why I became incontinent. And so, so, so, that first few months it's, I was very, very, I'm was very displeased with the doctor's activities and actions towards me. It's as if he had just, you know, I got the surgery, I got the money, we'll worry about that later and so, that kind of rubbed me wrong.

Five couples described ambiguity regarding the diagnosis of prostate cancer, as well as a lack of clarity regarding the implications this diagnosis would have on them. These couples described not being sure of which treatment options were best, nor what long-term consequences would be:

Male: It was a harder time because it wasn't clear, like, I've, I talked to other men. They said, 'Yeah yeah, all core samples came back and had cancer' and it was really, really clear what they needed to do.

Female: Oh, all of theirs had cancer in them?

Male: And another guy said, 'Well, about half of them came back.' You see mine, it wasn't clear it looked like just the beginning stages and so I finally I just said okay I have to, so I just made the decision and I didn't want the idea I didn't like the idea cancer was in my body sore didn't want to wait.

Female: And also radiation remember was going to.

Male: The consequence of radiation were....

Female: The consequence of radiation were, you couldn't have surgery after radiation.

Male: After radiation...

Female: Because the tissue was damaged.

Male: The cell damage.

Female: This issue is damage because of the radiation so you can't remove the prostate later.

Male: So, if it comes back, which is a possibility and my age, I'm younger...

Another ambiguous aspect of treatment and diagnosis was related to sexual functioning. Lastly, following treatment, two couples were unsure of whether, or how, their sexual functioning would return. A male partner from interview one describes his experience with ambiguity of sexual functioning:

I keep taking medication, um, laughs, medications expensive too, it forty dollars a pill. Only because they consider it recreational, that it's like Viagra, they consider it. I would take it for maintenance dose to keep blood flowing to the areas it didn't need to flow to and the the the pharmacy is charging it like I'm using it for recreational sex. Uh, so they charge like forty dollars a pill. I, I didn't know how expensive the medication was gonna be until I went to try and pick it up, and, he wrote me prescription I don't know how many pills, but, uh, it was like, and

ungodly amount to buy the pill. I had to buy four at a time, in fact I had to buy a 20 mg pill and since I was only supposed to have 5 mg a day. I had to cut the mg pills in quarters to be able to take the right dosage and everything else because the price of 20 mg and the price of 10 mg was the same. So the, the dealing with the whether or not things are gonna work, you know, in the long run. 'Cause I'm young enough or things just gonna work out with that. I, I've had to put that aside...

Not only did this male patient face ambiguity around sexual functioning, his experience indicates that there may be ambiguity in treating sexual dysfunction related to psychopharmacology. Overall, these couples continue to experience ambiguity in how the treatment options they have chosen will continue to affect them, and report a lack of clarity regarding whether their sexual dysfunction is permanent.

Approaches to Coping

In connection to the first research question regarding how couples facing prostate cancer experience distress, the couples interviewed provided a wealth of data regarding their approaches to coping. This second-level theme had four subthemes: faith and prayer, avoiding self-disclosure to avoid adding to spouse's burden, own research on cancer, and coping through acceptance. Two couples used faith and prayer as a way to cope with distress brought on by prostate cancer diagnosis and treatment. One wife expressed how they used prayer as couple: "With his strength, and with our prayers, um, I just I turned it over to the Lord. That's just basically what I did."

During the diagnosis and treatment phase of prostate cancer couples also described avoiding self-disclosure to avoid adding to spouse's burden:

Well, I had to be very delicate uh, very careful not to hurt his feelings, or make him feel that I was going to be uh, the one that was going to suffer from this.

Because he was very fragile. It was a terrible, terrible decision for him to have to make.

This female participant described being cautious about what feelings to share with her partner in an effort to not make him feel badly. Both male and female partners discussed wanting to protect their partner from further stress due to prostate cancer and the treatment process.

A theme prevalent across couples ($n = 4$) included reports that the patients and their wives actively worked to do their own research on prostate cancer and treatment options. An example includes a wife who stated, "You know, researching and figuring out how severe it was. But, I'm ok with it now. I'm glad it was me, I'm glad I could be there with him. It's just, it's hard." Another couple described their experience with research:

I'm not naïve either, but when you mention the word 'cancer.' you better do something about it, okay. And so, sure enough, I did not procrastinate. I took action to learn more about it and then, like I said, I went to two different urologists.

A common approach to coping, used by half of the couples interviewed, was coping through the acceptance of the diagnosis, treatment process, and aftermath of prostate cancer. The couples frequently, and specifically, used the word “acceptance” to highlight their orientation towards peace and tolerating a difficult situation. An example includes a husband who stated:

Ultimately, it was my decision, but it was her decision too, um... And, of the treatment options that I chose, consequences of all the treatment options were discussed pretty much in detail, back and forth. And then, once we made the decision on a treatment option that...it was just pretty much accepted and then we prayed together.

Unlike the experience of denial several couples used to describe other couples’ reactions, the couples interviewed presently reported they were able to acknowledge their diagnosis, treatment, and any side effects, and make the best of the circumstances.

Healthy Lifestyle Changes

As part of moving towards acceptance of the prostate cancer diagnosis and treatment, three couples made lifestyle changes to improve their health. This second-level theme had two subthemes: spousal encouragement of health behaviors and adoption of positive health behaviors. Two male patients made positive health changes such as, watching weight, eating healthier and exercising. The wife from interview two described her experience watching her husband adapt positive health changes into his life:

he is still with us today, and uh, I'm sure that his angel was watching over him because we had the right doctor, we had the radiation, and from that time he has watched himself weight wise, but he had been doing that, but he was even more vigilant so he has lived a very healthy life

Two spouses helped to encourage these positive health behaviors by adapting to these changes as well.

Ya know what got me in the beginning was suddenly started watching his diet and reading up on everything. I just go into lets fix a lot of this lets not do this and then all of a sudden it wasn't any true anymore so I had to readjust my cooking (interview five).

These couples seemed to make healthy life choices in an attempt to move towards acceptance and maintain remission.

Changes in Intimacy

As couples moved through the treatment process, many experienced changes in intimacy. These changes were reflected in the following subthemes: sex less important than intimacy, sexual functioning sacrificed for other organ functioning/survival, and alternative non-sexual forms of intimacy. Half of the couples described the importance of closeness given the fact that sexual functioning has worsened, and their sexual relationship had declined. They described these changes, and move towards alternate definitions of closeness and intimacy, in multiple ways. One couple described a decreased focus on sex, with a priority on intimacy as the following:

We're both very cognizant of what this diagnosis meant especially when you have surgery and, they've asked me, now this may affect our sex life, and my, answer to him was I'd rather have you without sex than not to have you at all. That's how I felt, that's how I still feel (interview two).

An example of a shift in the relative importance couples placed on intimacy is reflected in the fact that couples interviewed often chose survival/other organ functioning over sexual functioning. One man from interview six explained the choice he and his medical team faced:

Even though they did my surgery robotically, which means there were cameras and magnification, and that certainly helps. But they can't say, 'OK, I need to, I need to let the gentlemen retain some sexual functionality and leave some cancer there.'

Due to this decision, all but one couple described alternative forms of intimacy. "We find other ways to express affection. We're great at hand-holding and touching. Uh, I think our relationship may be better today than it was 23 years ago." Couples describe hand holding, "fooling around," touching, and kissing as other forms of intimacy as well.

Advocacy

The theme of advocacy was present in all but one of the interviews conducted for this research study. Five of the couples described being involved in prostate support groups, and described the benefits of these support groups. These couples also seemed to accept the impact that prostate cancer had on their lives and their relationship, and

seemed to move towards meaning-making by mentoring others through the support group. Others shared information, resources, and support with patients that were outside of their prostate support groups. An example includes a patient who explained:

This lead me later on to, uh, forming a coalition where we, uh, educate other patients, uh, other survivors on, um, on things you have to ask the doctor. Um, um, our own experience with side effects, uh, this type of nature. Not to make recommendations on treatment, because this is, we are not medically trained.

Perhaps these couples are creating new positive meanings behind why they were diagnosed with prostate cancer. Per couples' reports, by choosing to attach new meanings to cancer, they are able to find a sense of purpose to something that may be otherwise negative and meaningless.

Gender Differences in the Experience of Distress

The theme of gender differences in the experience of distress is reflective of the following research question: *Do female partners experience distress differently than the male patient? If so, why? And, is distress for the female partner connected to experience of sexual dysfunction?* The research team found the following subthemes (open codes) in the data: differences in how spouses react and cope, and men don't talk about cancer/ignore it.

While some partners experienced distress similarly, other couples did not, or they reported experiencing certain aspects differently. Several female spouses identified other

women in support groups as having feelings of resentment or bitterness towards male partners, an experience they believed was unique to wives. For instance:

Female: I don't think they deal with, like I did. I think many women uh, uh, hold, hold it against their husbands. I think many women are angry. I think they resort to other means, and I don't mean being promiscuous. Uh, but I think they can't, I don't think they....

Male:...Accept...

Female...Accept it the way I did. But the reason for that, I think, is they weren't as well educated on the subject. They didn't understand the working of a man's body as well as I did, and they didn't realize the guy just didn't have a choice if he wanted to live. And I've always had, uh, I've always been a caretaker, I'll put it that way. 'Cause I know, in my experience, some of the women, and they're just bitter, so on the whole, I don't know too many that fit, that dealt with it the way I did, you know, without bitterness.

In addition, several male and female spouses described gender differences regarding how men and women talk about cancer. An example includes:

Yeah, we don't, we just don't talk about it. I mean, there's reasons the number two killer of all cancers and only men get it – because we don't do anything about it. We don't talk about it. Um, I really don't want to talk about it, um, still. Um, but I do tell my friends who, you know, 'Get your PSA check, go get get some baseline. Get, you know, um and, um, if nothing at all, go see your urologist, you

know. Go see two, you know, 'til you're comfortable with it.' But, uh um, I mean, men, men, because they have such a hard time talking about it, it has to be communicated in some other way, that men are receptive to, however men receive information.

Half of the couples, like the one above, believed that men often do not talk about cancer and often ignore treatment symptoms and side effects. While some partners experienced distress similarly, other couples did not. Two couples also described differences in coping with prostate cancer, such as experiencing men experiencing depression instead of women's experiences of anxiety. Spouses also differed in their views of which spouse had it harder. When talking about how each partner has coped, one couple in particular disagreed with their spouse's perceptions of their experience. For example, they (interview one) stated:

Female: Yeah, I have more stress than just yours and, I don't...that's not really true that I'm struggling with stress. I do really well with stress, and I'm struggling physically. Being tired from taking care of everybody. Emotionally I'm OK, physically I'm exhausted.

Male: Well let's see, from *my* side of this street...of the fence, it looks like it, uh, emotionally mentally wears you down.

Communication About Distress

Two themes, communication issues and positive healthy communication, are reflective of the following research question: *How do couples communicate about*

stressors? Do individuals think their partner knows they are distressed? Does the partner actually know? Multiple subthemes were identified in each of these two themes.

Communication Issues

Couples in the present study identified communication issues represented in three open codes: closed communication, spousal disagreement, and difficulty discussing sexual functioning. Two couples identified experiencing communication issues such as difficulty getting a partner to open up. One wife from interview five described her experience with trying to have her husband open up: “Ummm...he was very quiet, uh, it was kinda hard sometimes to figure out what he was thinking and, uh, I had to ask a lot of questions and sometimes he would kinda be, blah, kinda grumpy... grouchy.” Three couples also experienced spousal disagreements, including arguments throughout the process of diagnosis and treatment. One couple from interview four identified their spousal disagreements:

We’re gonna have fights like every couple does. We are gonna have our differences. Um, um you know what the, thing, old saying says, ‘You can’t teach an old dog new tricks.’ So you know, we still have our quarrels, I still have my criticisms. She doesn’t like me to be negative, I complain about drivers all the time.

Lastly, two couples described difficulties discussing sexual dysfunction (including erectile dysfunction, decrease in sexual desire, etc.). An example from one wife (interview three) and her experience discussing sexual functioning:

You were now six months into it so and the sexual dysfunction is, it's a concern.

It's, um, difficult as a couple to even talk about it, for us together to talk about it.

And, I think that we still need to figure that out.

Positive, Healthy Communication

Despite these communication issues, all couples described examples and processes reflective of positive, healthy communication. The research team identified three subthemes related to positive, healthy communication: positive communication, empathizing with partner, and lack of change in communication. All couples described communicating positively by doing one or more of the following things: being honest about their feelings, focusing on their present concerns, not hiding things. These couples also emphasized discussing their feelings and emotions at the appropriate time, like the following male participant describes:

I think timing is important. Um, you know, most of the time, before I want to talk to her about my feelings, I'm going to process them myself internally. So I'm gonna keep them to myself internally for some period of time as that I need to process my thoughts through this. Okay, depending on the thought, it's gonna be a different timeframe, you know, but it just, until I feel ready. So I will almost always keep it to myself until I'm ready to express them and I processed them and thought them through and come to a point where I wanna talk to her about it. Um, and then maybe that I process them enough that I feel like I don't need to talk to her about it. I'm, I'm okay with it and so there's no reason to talk about it. Okay

that may be a decision I make. Um, but if I haven't then we'll talk about it when I feel that the timing is right and you know I'm in the mood. And, um and uh, I feel may be I feel like maybe it's a time right. Maybe she's had a day where she, it's, she's more open to talking about it.

Female partners also described being supportive and understanding of their partner's experience:

I think, once I knew what his, what he had to contend with from my point of view, the only thing that I could do is to make it as simple as okay as possible. And, to me, you know, the only... I want to reassure him he's still the man that I married, is still the same guy, if not more, like Superman in a way, For his age, what he can accomplish is unbelievable, you know? It's just like, whatever he decides to do, you better look out because he's gonna do it. So, uh, I'm happy.

Like this wife, two other couples expressed being supportive and understanding of one another in an effort to be empathetic.

Four couples described a lack of change in communication. An example includes: "Communication hasn't changed. Um, I think we both are at a point at least now where we know there's a problem and we have to deal with it and uh, um hopefully on the right path that I need." This couple, from interview five, described experiencing no changes in communication, thus maintaining the same pattern pre and post prostate cancer.

Summary

In conclusion, several themes were found related to the three research questions. Couples experienced distress in many different ways, through distressing emotions, lack of support from medical staff, and through medication and treatment side effects. Despite these stresses, couples described methods of coping and work to advocate for other prostate cancer patients and their spouses that they experienced as positive and beneficial (to themselves and to these other couples). The research team also identified gender differences in adapting to the cancer diagnosis and treatment, including gender differences in the experience of resentment and bitterness and differences in how men and women communicate about cancer. Lastly, couples described positive, healthy communication processes, as well as communication issues, that impacted their conversations about cancer and its sexual dysfunction. All themes (and subthemes) described are reflective of a minimum of two participants providing data tied to that theme, and therefore meaningful and representative of the present sample.

CHAPTER V

DISCUSSION

Previous literature has highlighted the limited amount of research in the area of prostate cancer, couples, distress, sexual dysfunction, and communication (Badr & Carmack-Taylor, 2009). The present study was able to identify themes related to how couples experience distress, such as, distressing emotions, lack of support or information from medical professionals, and medication/treatment side effects. In addition, we discovered themes involving gender differences, including differences in how men and women react to and cope with the prostate cancer, as well as men's lack of communication around prostate cancer. Themes regarding communication included communication issues (e.g., difficulties discussing sexual functioning) as well as positive, healthy communication.

Similarities to Previous Research

While the couples in the present study experienced distress, many couples also discussed having positive, healthy communication and empathizing with their partners about their experience. These couples also identified coping through acceptance of the diagnosis and treatment process and described moving towards advocacy through informing other patients and couples about their experience and community resources they could access. It may be that the couples interviewed have experienced decreased distress due to their use of positive communication with each other and through giving

back to the prostate cancer community. Similarly, Manne et al. (2010) found that couples experiencing prostate cancer who reported practicing open communication (i.e., mutual expression of feelings, discussion of cancer-related concerns) have higher marital satisfaction and lowered distress. In the present study, some couples were caregivers for one another as well as for other family members. It is unclear from the present findings whether this caregiving universally led to increased distress, as it has been shown to do in previous research (Harden et al., 2006).

In addition, the couples in the present study identified fears around loss or death similar to previous research (Lindau et al., 2011). One study speculated that this fear may be linked to sexual dysfunction. This study however identified that all men struggled with sexual dysfunction after treatment had been completed. This perhaps indicates that there is not a connection between fear of loss or death and sexual dysfunction. Some studies indicate that sexual dysfunction may be linked to functioning or lack of functioning before the diagnosis (Tan et al., 2011). Despite these findings the couples in this study all identified as having normal sexual functioning previous to treatment. Only incurring sexual dysfunction after undergoing treatment for prostate cancer.

When discussing sexual dysfunction, the present couples expressed difficulty communicating about the dysfunction and decrease in sexual desire. However, these couples were able to communicate about their desire to maintain intimacy, over and above their sexual functioning. This is similar to the disparities that Boehmer and Clark (2001) discovered when examining communication around sexual dysfunction in couples

facing prostate cancer. Nonetheless, couples seemed to struggle with communicating specifically about sexual dysfunction and disinterest. Similar to previous research (e.g., Boehmer & Clark, 2001; Gray et al., 1999), the present couples identified that, while sexual dysfunction was present, they would rather have sexual dysfunction than not surviving or losing other organ functioning.

The couples in this study, like others, had changes in intimacy due to the loss of sexual functioning. The present couples were able to focus on new forms of intimacy, such as hand-holding, touching, and kissing, similarly to couples in previous studies (e.g., Flynn et al., 2011; Lindau et al., 2011). One couple identified having a better relationship now than they did before they had prostate cancer, due to a desire to live with sexual dysfunction then not to live at all. This finding is also similar to previous research highlighting a focus on sexual functioning and mortality versus survival (e.g., Flynn et al., 2011; Lindau et al., 2011). Lastly, similar to previous research, the present couples described having different levels of sexual desire, unrelated to prostate cancer. These prior levels of intimacy and sexual activity may have impacted couples' abilities to make changes to intimacy, similar to a finding by Lavery & Clarke (1999).

Dissimilarities with Previous Research

Previous research investigating couples experiencing prostate cancer (Manne et al., 2010) has discussed the impact that sexual dysfunction has on distress. Specifically, men often have higher distress than their female partners due to urinary incontinence and erectile dysfunction. These experiences of men's distress is believed to have, in turn,

impacted women's higher levels of distress (Manne et al., 2010). The present study did not have a similar finding. Due to the qualitative nature of this study, it was not possible to determine if women faced *more* distress than men. However, findings for this study demonstrate that all couples experienced some form of distressing emotions, such as anger and depression. In addition, the couples described differences in how they cope with prostate cancer, how they discuss sexual functioning, as well as communication issues. Despite these findings, there was no identifiable link between male sexual dysfunction and female distress, unlike Manne et al.'s (2010) findings. While some studies have identified that women experience greater distress (e.g., Manne et al., 2010), the present study was unable to make any similar correlations.

In addition, Harden et al. (2006) speculated, in their analysis of couples experiencing prostate cancer, that women who work outside the home tend to face higher levels of distress compared to their non-working counterparts. Throughout the present study, three women identified as working outside the home during their husbands' diagnosis and treatment processes. However, the present findings were unable to make a correlation between gender, employment, work-life stress spillover, and partner increased distress.

Lastly, previous research (e.g., Flynn et al., 2011; Lindau et al., 2011) discovered that couples attempted to maintain a sense of normality by maintaining intimacy and sexual functioning. These couples repetitively described sexual activity as a significant piece of their quality of life, with descriptions of loss of sexual functioning as devastating

and life-altering. Although the sample in the present study was almost entirely limited to couples for whom only the male partner had a serious medical condition, many couples in the present study focused instead on attempting to maintain a sense of normality by attempting normal day-to-day activities, such as work and caregiving. This is in contrast to research that highlights that the importance of sexual activity diminishes only when both partners have a chronic illness (Flynn et al., 2011). Although the loss of sexual functioning was distressing for the present sample, themes overwhelmingly demonstrated couples' focus on alternative forms of intimacy, maintaining closeness and a focus on survival, and positive, healthy communication reflective of partners' empathy and support for one another.

Gender Differences & Advocacy

Unique themes regarding gender differences were also identified in the present sample. Couples identified that men tend to not discuss their experience with prostate cancer. Through their support groups and experiences with other couples facing prostate cancer, couples also identified their awareness that women may experience bitterness or resentment towards their male partners. Gender differences around coping, such as depression versus anxiety, were also identified. Another unique outcome of this study was the importance of advocacy through support groups or to other prostate cancer patients. All the couples in this study discussed their involvement in their support groups and advocating their experiences, although this finding may be unique to the present sample (i.e., which was recruited through prostate cancer support groups). The present

themes highlight that couples felt the need to advocate and inform other couples about coping with and surviving prostate cancer in order to fully accept their own experience with prostate cancer. An interpretation of this finding may be that the present couples are attempting to find new meaning behind an experience that could otherwise be negative and traumatic.

Clinical Implications

Several implications can be made for the mental health community, as well as the medical community. It is important to note that these implications are connected and therefore make an emphasis for more collaborative care within mental and physical health. Like many studies these couples identified ambiguity in treatment. Many couples identified disappointment in their medical providers. Couples felt that they were unsure of what the diagnosis meant, how they should proceed with treatment and the impending impact on their sexual functioning. It would be helpful for medical professionals to spend more time focusing on these concerns with patients and their spouses. Ideally it would be more beneficial to have mental health provider's work with the doctors and the patients throughout the whole process, from diagnosis to aftercare.

If mental health providers are working in a non-collaborative care setting it may be important to focus on couple's communication about their feelings, emotions, fears and concerns around diagnosis, treatment and sexual dysfunction. Therapist should know that couples have identified discomfort disclosing about sexual dysfunction and their disinterest in sex. Therefore it may take longer to help couples open up around this topic

however, this topic is important to discuss. It is important to note that any communication with medical providers may help connect the relational impact and the medical impact that couples face.

Marriage and Family therapist should be aware of the distressing experience of couples facing prostate cancer. Therapist should be aware that these couples may struggle to make a therapeutic alliance if they experienced lack of support and information from medical staff. Marriage and Family therapist may have difficulty getting these couples to open up about their feelings and emotion, due to their experience of having to put their feelings aside for their partner. Working with these couples may take longer due to emotional distress. However, for this very reason it is important to work with these couples.

Limitations and Future Research

Although this study adds to the literature on couples facing prostate cancer, it also has limitations. The researcher had limited privacy when in participants' homes. Two couples were unwilling to separate during the individual sessions. Due the interviews taking place in the participant's home, the researcher was limited on alternatives. Another limitation to in-home interviews is that participants may or may not have been able to hear their partner during the individual interview portion depending on where they went in the home. Participants were also easily distracted while in their home, including by beverages and telephones ringing, unlike those that were interviewed at the TWU campus or the public library.

However the public interview settings had their own limitations. Participants and the researcher did not have the ability to enforce privacy in public settings and therefore could be interrupted by others. Another limitation is that the participants may be easily distracted by new surroundings that they are not used to.

Limitations to face-to-face interviews meant that the researcher was limited to participants who were able to commute to another location or who were willing to allow the researcher in their home. This also limited those that are not able to travel due to physical limitations or those who were willing to participate but unwilling to allow someone into their home or unwilling to travel.

The present sample was homogenous, with participants having similar education status, similar ethnic identity and similar stages of diagnosis. This factor limited the ability to investigate ethnic or cultural differences similar to other studies (Harden et al., 2002). This may be an area for future research to target a more heterogeneous population.

As Harden et al. (2002) pointed out qualitative data is intended to look at a specific topic. Due to the qualitative nature of this study the findings gathered are not generalizable to all prostate cancer patients. This also means that the findings have less validity. With a small sample size the research findings may not be significant.

Due to the homogenous nature of this population future research may want to look at a more ethnically diverse population. As well as a more diverse age and stage at onset. This study looked at married heterosexual couples, it may be important to look at more diverse couples. Such as, same-sex couples, married or cohabitating. As well as

heterosexual couples who are cohabitating as well. It may be beneficial to look at a mix of this population to allow the researchers to distinguish differences. Since couples in this study participated post diagnosis, research should also look at couples pre and post diagnosis. Research may benefit from looking at the same sample longitudinally, from diagnosis to post treatment. Future research should also look at the role that religion and/or spirituality plays on discussion of sexual dysfunction within the couple and with others, including the role that prayer plays in coping with distress. Looking at this is especially important given the fact that research is limited in this area, however couples are identifying it as a way to cope with prostate cancer. Research should also look at couples in integrated settings to identify if integration makes an impact on the prostate cancer.

Conclusion

Couples facing prostate cancer face many distressing factors. This distress that couples face range from distressing emotions, medical and treatment side effects, and lack of support from their medical team. Despite these stressors couples are able to use coping skills, advocacy and their normal routine to cope with distress. Many of these couples were able to maintain their normal open communication. However, some couples found that they had closed communication which sometimes would be specifically around sexual dysfunction. Couples in this study also identified gender differences around bitterness, how men and women cope and men's lack of communication about prostate cancer. There is a need for marriage and family therapist to work with couples

facing prostate cancer. Specifically related to the distressing emotions these couples face and the impact this will have on their relationship. As well as working with them to open up again about their feelings and emotions related to these experiences as some couples may not have processed them during the diagnosis and treatment process of prostate cancer.

Table 1

Research and Interview Questions.

Research questions	Interview questions	Type of question
How do couples facing prostate cancer experience distress, and why? How is the distress connected to sexual dysfunction, related to prostate cancer and its treatment process?	1) How did you come to be diagnosed with prostate cancer? What has been the impact of the diagnosis and any treatment on you? Your spouse?	Male partner
	2) How has your spouse attempted to cope with the diagnosis and treatment?	Couple together and separately
	3) How have you attempted to cope with the diagnosis and treatment?	Together and separately
	4) As a result of the diagnosis and treatment of prostate cancer, in what ways is your life similar to or different from other couples your age who are not living with prostate cancer?	Together
	5) What symptoms or complications have you experienced that are troubling to you as individuals and as a couple? How do you manage them?	Together
	6) Have there been changes in your sexual relationship since diagnosis? Has sexual functioning been affected by treatment?	Together and separately

<p>Do male and female partners experience distress differently? If so, why? And, is distress for the female partner connected to experience of sexual dysfunction?</p>	<p>7) In general, do you think men and women deal with these kinds of situations, such as coping with prostate cancer, differently? How?</p> <p>8) How have you and your spouse dealt with sexual dysfunctions? Is there any difference between how the two of you deal with it?</p>	<p>Together</p> <p>Together and separately</p>
<p>How do couples communicate about stressors? Do individuals think their partner knows they are distressed? Does the partner <i>actually</i> know?</p>	<p>9) How have you and your spouse been communicating with each other recently? Is this pattern long standing, or has it changed as a result of the illness?</p> <p>10) How do the two of you communicate about sexual dysfunction related to the prostate cancer diagnosis or treatment? Did you talk about it before diagnosis?</p> <p>11) How do you decide when to talk with your partner about what you are thinking and feeling? Do you feel it's important to sometimes keep your feelings to yourself?</p>	<p>Together and separately</p> <p>Together</p> <p>Separately</p>
<p>N/A</p>	<p>12) Is there anything else you think it would be helpful for us to know regarding your</p>	<p>Separately</p>

	experience with prostate cancer?	
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Table 2

Themes and Sub-themes

Theme	Sub-theme	Participant interview numbers	Example
Distressing Emotions	Feelings of Anger, fatigue, depression, anxiety	12,346(anxiety)	“unless I’m on hormone therapies, uh, at which time you are limited, uh, because of fatigue....”
	feelings of regret surrounding the loss of sexual function	3	“If we had known that...that regret I have is that we didn't really have one really good night of just intimacy before he started that prep, or even earlier,”
	fear of loss and death	13	
	feeling emasculated	3	
	Feeling demeaned	2	Female: Pads, we used pads. Male: We had to, at the very beginning I had pads. Female: You used my pads. (laughs) Male: Yeah...it uh... Female: But we worked it out. Male: Yeah, the man me, had to uh... Female: It’s demeaning. Male: Uh, well... Female: It’s demeaning.

			Male: It takes away the macho part of me in this.
Medication and Treatment Side Effects	medication/treatment side effects	15 (hormone)23456 (incontinence)	Well I uh she has been very understanding, uh, um, although I had was far as. I had two issues, incontinence and um, erectile dysfunction as a result of the surgery. As far as the uh, the incontinence she's been very supportive. And um and since she's a nurse she she can helped out and give me the proper, the pads that um that uh pads that I can use. So she's been really good at that um as far as um the sexual situations she has been very understanding
	sexual dysfunction	123456	See above quote
	memory loss	1	you're rolling things are going good, then all of a sudden I can't remember something, and I get frustrated
	inability to care for partner in the way they were able to prior to cancer	1	My first cancer, uh I was I was the physical one, I was the one that took care of her, before I got cancer the first time. And then afterwards I was trying to build myself back to take care of her again because of her physical problems.

Lack of Support or Information from Medical Professionals	physician insensitivity to psychosocial issues and patient differences	14	<p>We were kind of disappointed um, he was disappointed in his doctor. He, he, was not crazy about how his doctor related to him. We, we, did find another doctor that was in his same group but much more receptive to him and much more a better bedside manner. So I think from that standpoint he's, she's done better he has more confidence in the second doctor. The first doctor would say these things and it kind of sounded like a little bit off hand to him, like you know, like it's okay, you know, like that kind of thing. And I don't think he (husband) was prepared to hear what he did hear the first time we were seen by the doctor. I think probably if I were to recommend anything I would think, people that get the diagnosis unless they say it's at stage IV that you should go at least for second opinion to another surgeon and then, or go back to the</p>
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Ambiguity in treatment options/outcome	23456	<p>same doctor and review everything.</p> <p>Male: it was a harder time because it wasn't clear like I've, I talked to other men they said yeah yeah all core samples came back and had cancer and was really really clear what they needed to do. Female: oh all of theirs had cancer in them?</p> <p>Male: and another guy said well about half of them came back. You see mine, it wasn't clear it looked like just the beginning stages and so I finally I just said okay I have to, so I just made the decision and I didn't want the idea I didn't like the idea cancer was in my body sore didn't want to wait.</p> <p>Female: and also radiation remember was going to. Male:the consequence of radiation were....</p> <p>Femalethe consequence of radiation were, you couldn't have surgery after radiation. Male: ..after radiation...</p> <p>Female:because the tissue was damaged. Male: the</p>
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		cell damage. Female: this issue is damage because of the radiation so you can't remove the prostate later. Male: so if it comes back which is a possibility and my age I'm younger okay and then I also studied online
Ambiguity in future sexual functioning	13	I keep taking medication, um, laughs, medications expensive too, it forty dollars a pill. Only because they consider it recreational, that it's like Viagra, they consider it. I would take it for maintenance dose to keep blood flowing to the areas it didn't need to flow to and the the the pharmacy is charging it like I'm using it for recreational sex. Uh, so they charge like forty dollars a pill. I, I didn't know how expensive the medication was gonna be until I went to try and pick it up, and, he wrote me prescription I don't know how many pills, but, uh, it was like, and ungodly amount to buy the pill. I had to buy four at a time, in fact I had to

		<p>buy a 20 mg pill and since I was only supposed to have 5 mg a day. I had to cut the mg pills in quarters to be able to take the right dosage and everything else because the price of 20 mg and the price of 10 mg was the same. So the the dealing with the whether or not things are gonna work you know, in the long run, cause I'm young enough or things just gonna work out with that. I, I've had to put that aside...</p>
Dissatisfaction with medical provider	4	<p>Then with the fact that he, that should have been a red flag whenever he called a couple times. Like you're pushing the issue okay, you got to do something that, that. That time I should've just, should've been red flag and I need to get a second opinion and, um, but I didn't, I didn't. And after the surgery, uh, that the doctor would not respond to my phone calls. I have my catheter seemed like urine was coming outside of the catheter.</p>

			<p>And um ,had to use a catheter for two weeks and then I'll, I won't get a call back from the doctor or the nurse so, and I cannot blame that lack of, that lack of, lack of, not interest but lack of action why I became incontinent. And so, so, so, that first few months it's, I was very, very, I'm was very displeased with the doctor's activities and actions towards me. It's as if he had just, you know, I got the surgery, I got the money, we'll worry about that later and so, that kind of rubbed me wrong</p>
Positive Treatment Experiences	biopsychosocial approach to treatment	1	<p>it cancer it doesn't matter if its prostate cancer it doesn't matter whether it's lung cancer or anything else uh, I've seen enough of the people and the progress and the diagnosis an everything else form working in the hospital to being a patient to know that people have to stay human</p>
	advances in treatment/future treatment options	2456	<p>I would say unless than a decade even less than that the entire</p>

			procedure will be done by robots.
Approaches to Coping	faith and prayer	236	“With his strength, and with our prayers, um, I just I turned it over to the Lord. That’s just basically what I did.”
	coping by venting	1	I think I cope with that by venting. I vent to my mom, um I’m a good venter, it’s healthy. So I vent to and talk to people
	own research on cancer	13456	You know, researching and figuring out how severe it was. But, I’m ok with it now. I’m glad it was me, I’m glad I could be there with him. It’s just, it’s hard.”
	Coping through acceptance	123	Ultimately, it was my decision, but it was her decision too, um... And, of the treatment options that I chose, consequences of all the treatment options were discussed pretty much in detail, back and forth. And then, once we made the decision on a treatment option that...it was just pretty much accepted and then we prayed together.
	Coping by distractions	1	So I, uh, spent the entire time of radiation working by myself,

			when there was supposed to be four of us working. So it was one of those things where it gave me a lot of distractions and different things
Partner/Spouse Protective Behavior	Partner taking control	1	um, yeah I mean I think that's more um, I've made him take more ownership of it, he gets really comfortable, um, because I can take charge I'm very organized and it'll be like when some comes to take care of him, and I'll be like I set everything up, I have everything ready, I have his food ready, I have this ready, and, then I can go and know he's gonna be ok in case he forgets or something and so.
	avoiding self-disclosure to avoid adding to spouse's burden	1235	Well, I had to be very delicate uh, very careful not to hurt his feelings, or make him feel that I was going to be uh, the one that was going to suffer from this. Because he was very fragile it was a terrible terrible decision for him to have to make.
	Empowering the patient	1	now it's sorta like you call you medication thing, you make your

			appointment, you do this, you know I'm giving him back, trying to empower him to be more active
	protective of partner	1	that was hard especially when I'm seeing her struggle physically and emotionally the last thing I want to do is put more stress on her
	go without/self-sacrifice	1	so she would, she would go without, she had, she needs shot or something that she was supposed to be taking she would go without, so, uh, and, and it's not like I didn't know so, that was hard
Maintaining Normalcy	attempting to be helpful/back to normal	1	all I kept to myself was that I had to get back to having a life again, and to me that meant that I was gonna have to be able to do things for her
	lack of change in communication	2356	"communication hasn't changed um I think we both are at a point at least now where we know there's a problem and we have to deal with it and uh, um hopefully on the right path that I need."
	mutual caregiving	1	it's just seems that uh uh now its its were having to find our way back through all the

			rest of the stuff in order to be able to do that but I you know we've always love each other, we've always taken care of each other, one of the reasons we got together in the beginning was I was trying hard to take care of here when she was going through some of her surgeries. So, um, were both care givers, the only problem is that I'm not very good at it now
	caregiving for others	1	I'm the caretaker of everyone
Healthy Lifestyle Changes	spousal encouragement of health behaviors	15	Ya know what got me in the beginning was suddenly started watching his diet and reading up on everything. I just go into lets fix a lot of this lets not do this and then all of a sudden it wasn't any true anymore so I had to readjust my cooking
	adoption of positive health behaviors	25	he is still with us today, and uh, I'm sure that his angel was watching over him because we had the right doctor, we had the radiation, and from that time he has watched himself weight wise,

			but he had been doing that, but he was even more vigilant so he has lived a very healthy life
Changes in Intimacy	sex less important than intimacy	123	We're both very cognizant of what this diagnosis meant especially when you have surgery and, they've asked me, now this may affect our sex life, and my, answer to him was I'd rather have you without sex than not to have you at all. That's how I felt, that's how I still feel
	sexual functioning sacrificed for other organ functioning/survival	1256	Even though they did my surgery robotically, which means there where cameras and magnification and that certainly helps. But they can't say ok I need to I need to let the gentlemen retain some sexual functionality and leave some cancer there
	alternative non-sexual forms of intimacy	23456	"We find other ways to express affection, we're great at hand holding and touching. Uh, I think our relationship may be better today than it was 23 years ago."
Advocacy	Benefits of support groups	23456	this lead me later on to uh forming a coalition where we uh educate other patients uh other survivors on um on

			things you have to ask the doctor um um our own experience with side effects uh this type of nature not to make recommendations on treatment because this is we are not medically trained.
	Serving as informational resource for other patients	3	I'm certainly not the expert I just you know what my whole process was and was happy that I made the decision where other men that did the radiation and I've been extremely successful. But, they've asked me about my decision, like, just like my decision-making process just like I've explained it to you and but I don't think there any different as a couple.
Differences in how partners experience distress	Differences in how spouses react and cope	15	Well let's see, from my side of this street...of the fence, it looks like it, uh, emotionally mentally wears you down
	Resentment/bitterness	2(others) 4 (towards doctor)	
	Men don't talk about cancer/ignore it	346	Yeah, we don't, we just don't talk about it. I mean, there's reasons the number two killer of all cancers and only men get it – because we don't do anything about it. We don't talk about

			<p>it. Um, I really don't want to talk about it, um, still. Um, but I do tell my friends who, you know, 'Get your PSA check, go get get some baseline. Get, you know, um and, um, if nothing at all, go see your urologist, you know. Go see two, you know, till you're comfortable with it.' But, uh um, I mean, men, men, because they have such a hard time talking about it, it has to be communicated in some other way, that men are receptive to, however men receive information.</p>
Communication Issues	Difficulty discussing sexual functioning	35	<p>You were now six months into it so and the sexual dysfunction is, it's a concern. Its um difficult is a couple even talk about it for us together to talk about it and I think that we still need to figure that out</p>
	Spousal disagreements	134	<p>We're gonna have fights like every couple does, we are gonna have our differences. Um um you know what the, thing, old saying says you can't teach an old dog new tricks. So you know we still have our quarrels, I still have my criticisms. She</p>

			doesn't like me to be negative, I complain about drivers all the time.
	Communication issues	35	"Ummm...he was very quit uh it was kinda hard sometimes to figure out what he was thinking and uh I had to ask a lot of questions and sometimes he would kinda be blah kinda grunm... grouchy."
Positive, Healthy Communication	Empathizing with partner	134	I think, once I knew what his, what he had to contend with from my point of view, the only thing that I could do is to make it as simple as okay as possible. And, to me, you know, the only... I want to reassure him he's still the man that I married, is still the same guy, if not more, like Superman in a way, For his age, what he can accomplish is unbelievable, you know? It's just like, whatever he decides to do, you better look out because he's gonna do it. So, uh, I'm happy.
	positive communication	132456	I think timing is important. Um you know most the time, before I want to talk to her about my feelings I'm going to process

them myself internally. So I'm gonna keep them to myself internally for some period of time as that I need to process my thoughts through this. Okay, depending on the thought it's gonna be a different timeframe, you know but it just until I feel ready. So I will almost always keep it to myself until I'm ready to express them and I processed them and thought them through and come to a point where I wanna talk to her about it. Um and then maybe that I process them enough that I feel like I don't need to talk to her about it. I'm, I'm okay with it and so there's no reason to talk about it. Okay that may be a decision I make. Um but if I haven't then we'll talk about it when I feel that the timing is right and you know I'm in the mood. And um and uh I feel may be I feel like maybe it's a time right. Maybe she's had a day where she, it's, she's more open to talking about it.

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APPENDIX A

DEMOGRAPHIC AND MEDICAL HISTORY QUESTIONNAIRE

Demographic and Medical History Questionnaire

ID Number _____

Date _____

This questionnaire asks questions that describe some general characteristics about you. This information helps us understand general characteristics of the people who complete these interviews. Please CHECKMARK one response to each item.

1. Age: _____ years
2. Sex: ☐Male ☐Female
3. Please indicate your current **Relational Status**:
 - ☐Married and living together
 - ☐Married but separated (not currently living together)
 - ☐Never married and cohabiting (living together)
4. How **LONG** have you been in this relationship?
 - ☐Less than one year
 - ☐1-4years
 - ☐5-9years
 - ☐10-14years
 - ☐15-19 years
 - ☐20-24years
 - ☐25-29years
 - ☐30-34years
 - ☐35-40yeras
 - ☐More than 40 years
5. What is the **HIGHEST** level of education you have completed?
 - ☐Some high school (did not obtain GED)
 - ☐High school graduate or obtained GED
 - ☐Some college – no degree
 - ☐Associates degree
 - ☐Bachelor's degree
 - ☐Master's degree
 - ☐Doctoral/Professional degree

6. What is your race? (you may check MORE than one)

☐Black or African American

☐White

☐Asian

☐Native Hawaiian or Pacific Islander

☐American Indian or Alaska Native

☐Other

7. What is your ethnicity?

☐Hispanic or Latino

☐Not Hispanic or Latino

8. Age of prostate cancer diagnosis (of you or your partner):

☐18-30

☐31-40

☐41-50

☐51-60

☐61-70

☐71-80

☐Older than 80

9. Stage of prostate cancer diagnosis:

☐Stage 1

☐Stage 2

☐Stage 3

☐Stage 4

10. Treatment type:

11. Have you been diagnosed with any other cancer now or in the past?

☐ Yes

If Yes, please explain: _____

☐ No

12. Have you ever been diagnosed with any of the following?

Kidney Disease

☐ Yes

☐ No

Lung Disease

☐ Yes

☐ No

Heart Disease

☐ Yes

☐ No

Liver Disease

☐ Yes

☐ No

Hyper/Hypothyroidism

☐ Yes

☐ No

Seizures

☐ Yes (see below)

☐ No

If you answered **YES** to having been diagnosed with **SEIZURES**, was this due to the prostate cancer diagnosis?

☐ Yes

☐ No

☐ N/A

13. Have you experienced sexual dysfunction **following** the diagnosis of prostate cancer?

☐ Yes

If Yes, please explain: _____

☐No

14. Did you experience sexual dysfunction **prior to** the diagnosis of prostate cancer?

☐Yes

If Yes, please explain: _____

☐No

Thank you for completing this questionnaire!

APPENDIX B
RECRUITMENT MATERIAL

Recruitment Email

Hello,

We are looking for males who have been diagnosed and or treated for prostate cancer and their female partners to participate in a voluntary research study conducted through Texas Woman's University. Partners must be in a relationship, either married or living together. Male partners must be between the ages of 50 and 80, female partners must be at least 18 years of age. Both partners must be able to read, speak and comprehend English. The purpose of this research is to evaluate the relationship between prostate cancer and relationship distress in couples.

This research study includes a medical history questionnaire, a demographic questionnaire, and an interview. The interview will take approximately an hour and half to two hours to complete. Interviews will be recorded with an audio recorder. Participation in this research study is voluntary and you can end the interview at any time.

Feel free to share this with anyone else who may be interested in this research study. If you have any questions or would like to participate in this study, you can contact Kristin McDaniel at kmcdaniel1@twu.edu or her advisor Dr. Sarah Woods at swoods6@mail.twu.edu.

Kristin McDaniel, B.A.

Phone:

Email: kmcdaniel1@twu.edu

Sarah Woods, Ph.D, LMFT-S

Phone: 940- 898-2682

Email:

swoods6@mail.twu.edu

As with any electronic submission, there is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu.

YOU ARE INVITED TO BE A PART OF THIS STUDY



What is the relationship between distress in couples and diagnosis and treatment of prostate cancer? Your participation in an hour and half to two hour confidential interview could help answer this question.

You are eligible to be a part of this research study if you and your female partner (married or living together) agree to be interviewed about your experiences since the diagnosis and/or treatment of prostate cancer. You must be 50-80 years old. Your partner must be at least 18. You'll be asked to complete a brief medical history form, a demographic information form, and the audio-recorded interview conducted by me, Kristin McDaniel a family therapy graduate student completing my thesis research at Texas Woman's University. All information is confidential. This is a research study, all Participation is voluntary and you can withdraw from the study during any part, without any penalty.

May I tell you more?

Feel free to share this information with anyone else who may be interested in this research study. If you have any questions or would like to participate in this study, you can contact Kristin McDaniel at kmcdaniel1@twu.edu or her advisor Sarah Woods, Ph.D at swoods6@mail.twu.edu.

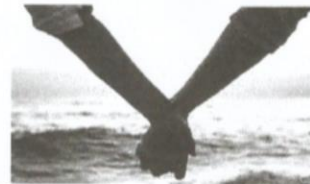
Kristin McDaniel, B.A.

Phone: [REDACTED]
Email: kmcdaniel1@twu.edu

Sarah Woods, Ph.D, LMFT-S

Phone: 940- 898-2682
Email: swoods6@mail.twu.edu

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APPENDIX C

CONSENT

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title of the study: Couples Experience Facing Prostate Cancer: Distress, Communication and Sexual Dysfunction.

Principal investigator: Kristin McDaniel, B.A.

Phone:

Email: kmcdaniel1@twu.edu

Faculty Advisor: Sarah Woods, Ph.D, LMFT-S

Phone: 940-898-2682

Email:

swoods6@mail.twu.edu

Explanation and Purpose of the Research Study

The purpose of this research study being conducted through Texas Woman's University is to evaluate the relationship between prostate cancer and relationship distress in couples.

For this study, participants will be males who have been diagnosed and or treated for prostate cancer and their female partners. Partners will be in a relationship, either married or living together. Male patients must be between the ages of 50-80 years old with female partners who are at least 18 years of age. Both partners must be able to read, speak and comprehend English.

Description of Procedures

This study includes a medical history questionnaire and a demographic questionnaire with such questions as race, age, gender, and relational length. This study also includes an interview that will take approximately 1.5 to 2 hours to complete. These sensitive interviews will be recorded with an audio recorder for the purpose of verbatim transcription. Participation is voluntary and participants can end the interview at any time.

Description of Potential Risks

One potential risk of participating in this study is loss of confidentiality. Only the principal investigator will have access to the recordings. Recordings will be kept in a locked box in a locked filing cabinet. Only the research team, principal investigator, faculty advisor and research team member will have access to the transcriptions. Transcriptions will be password encrypted and stored on an encrypted flash drive and

placed in a locked filing cabinet. Emails will be kept on a separate document that is password protected and locked in a filing cabinet. Questionnaires will be assigned an ID number. ID numbers and names will be kept on a master list separate from all data and stored in a locked filing cabinet in the faculty advisor's office. Confidentiality will be protected to the extent that is allowed by the law. There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. All data will be destroyed within five years after the end of the study. Participation is voluntary and you can withdraw from the study during any part, without any penalty.

A second potential risk of participating in this study is emotional discomfort due to the discussion of sex and the experience of a life threatening illness. Participants may take a break at any point of the interview without penalty. Participants may also resume the interview at another day if emotional discomfort is too high to continue the interview the same day. A list for mental health services is attached to your copy of the consent form. Mental health professionals in your area can also be found at http://www.therapistlocator.net/iMIS15/therapistlocator/Content/Directories/Locator_Terms_of_Use.aspx or <http://locator.apa.org/> Participation is voluntary and you can withdraw from the study during any part, without any penalty.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Description of Benefits

Participants will receive no direct benefit from participating in this study. The benefits of this study include helping those in the family sciences and medical field, such as, mental health providers, doctors, nurses and support group leaders to better understand the impact of prostate cancer on relational distress. Participants will be given the option at the end of the interview to receive information on the study results. Participants can voluntarily give their email to receive the study results.

Signature

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research

or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu.

Signature

Date

Referral List:

Mental Health Providers and Agencies Providing Counseling

Mental health providers in your area can be found at:

Therapist Locator: www.therapistlocator.org

- Clinical Members, American Association for Marriage and Family Therapy

Psychology Today: www.psychologytoday.com

- Professional listings for therapists, counselors, psychologists, psychiatrists, group therapy, and treatment centers

Specific to the Dallas-Fort Worth area:

Family Studies Center, UT Southwestern

- Connie Cornwell, Director
- 214-645-8300
- 6363 Forest Park Rd., Tower 2 – 7th Floor, Suite 722, Dallas, Texas

APPENDIX D

IRB APPROVAL



Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378
email: IRB@twu.edu
<http://www.twu.edu/irb.html>

DATE: June 15, 2015

TO: Ms. Kristin McDaniel
Family Sciences

FROM: Institutional Review Board - Denton

Re: *Approval for Couples' Experiences Facing Prostate Cancer: Relational Distress, Communication and Sexual Dysfunction (Protocol #: 18156)*

The above referenced study has been reviewed and approved by the Denton Institutional Review Board (IRB) on 6/11/2015 using an expedited review procedure. This approval is valid for one year and expires on 6/10/2016. The IRB will send an email notification 45 days prior to the expiration date with instructions to extend or close the study. It is your responsibility to request an extension for the study if it is not yet complete, to close the protocol file when the study is complete, and to make certain that the study is not conducted beyond the expiration date.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. A copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Karen Petty, Family Sciences
Dr. Sarah Woods, Family Sciences
Graduate School